

The national strategy for sexual health and HIV



A response from Sigma Research

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We welcome the publication of the draft strategy as a major step towards increasing the sexual health of the residents of England. We also welcome this opportunity to comment on the draft as a contribution to its further development. We comment specifically on our two main areas of expertise: research & development and HIV prevention.

1. Sexual health in England today - setting the scene

One of the original stated aims of the strategy was to develop a broader public health understanding of sexual health. However, the current draft is structured to limit the meaning of sexual health to those aspects addressed by NHS clinical services. Although paragraphs 1.1 and 1.2 suggest the strategy will adopt a broad and inclusive definition of sexual health, this is quickly reduced to concern about infections and conceptions. The absence of equitable relationships and sexual fulfilment mentioned in paragraph 1.2 are not described in later sections, nor are interventions to address them. The same is true of sexual assault and abuse. In addition, while the proposed approaches to meeting people's HIV and unwanted pregnancy needs are chiefly educational and community-based, the strategy concentrates on describing the funding and infrastructure of clinical diagnostic and treatment interventions.

This limiting of sexual health to the absence of infection/conception and the limiting of interventions to clinical NHS providers runs throughout the strategy and causes 'blind-spots' and gaps which will seriously limit the strategy's effectiveness. Below we outline how this might be addressed by making explicit the sexual health needs of the population which it is acceptable for NHS services to address. This also provides future commissioners with a template against which to assess local need.

In Chapter 1, this problem can be mitigated by a clearer definition of sexual health. While we applaud the values expressed in paragraphs 1.1 and 1.2, we think they provide a circular, limiting and unhelpful definition of sexual health.

PROPOSED ACTION:

- [1] We suggest that the description of sexual health (1.1 and 1.2) be replaced with a more thorough and actionable definition. We suggest:

Sexuality is an important part of our identity as human beings and sex is central to some of the most important and lasting relationships in our lives. Sexual activity also has important implications for physical and mental health. This strategy proposes a comprehensive and holistic definition of sexual health:

Sexual health is the foundation for having a safe and satisfying sex life.

It follows that protecting, supporting and restoring sexual health is important. Common causes of sexual ill-health are inequitable relationships, psychosexual problems, unwanted pregnancies and sexually transmitted infections, including HIV. Sexual health services are those interventions intended to address sexual health needs.

- [2] The box on page 7 could usefully elucidate the actual causes of poor sexual health (as well its consequences) the strategy seeks to address, as follows:

Poor sexual health: causes and consequences

Sexual health, the foundation for a safe and satisfying sex life, can be compromised by:

Low self-regard; low regard for sexual partners; absence of sexual choice; inadequate interpersonal and physical skills; ignorance about how to avoid disease transmission and unwanted conception; poor access to oral and intrauterine contraception; poor access to condoms and lubricant; lack of awareness of the presence of infection; poor access to reproductive technologies; poor access to the diagnosis, management or treatment of infections.

All of these unmet sexual health needs can contribute to inequitable relationships and failure to take protective measures which can result in exposure to:

- Chlamydia which can cause pelvic inflammatory disease, which in turn can cause ectopic pregnancies and infertility;
- HIV, which can cause AIDS;
- HPV, which can cause cervical and other genital cancers;
- HBV / HCV, which can cause hepatitis, chronic liver disease and liver cancer;
- HSV, which can cause recurrent genital herpes;
- Bacteria, which can cause vaginosis and premature delivery;
- Unintended pregnancies which can result in abortions and poor educational, social and economic opportunities for young women;
- Sexual coercion and abuse, which can result in social withdrawal, isolation, depression and suicide.

2. Aims and principles

Our fundamental concern regarding the second chapter is the assumption that 'prevention' = 'information giving' (see strategy sections 2.1, 2.2 and throughout) and 'services' = 'clinical interventions'. These assumptions lead to a belief that any provider of a clinical service is qualified to deliver any non-clinical prevention service. This is not the case and most prevention interventions require specific expertise. These skills and expertise must be acknowledged, valued and fostered if we are to collectively increase our impact on sexual health. We suggest solutions to these problems in the following sections.

3. Better prevention

While this chapter brings substantial clarity to many issues concerning preventative aspects of sexual health it is our concern that the process of subsuming HIV prevention into a broader sexual health agenda will be very detrimental to the target of reducing new infections by 25%. Our concerns are best addressed under three headings.

3a. Defining HIV prevention as a discrete and highly specialised activity.

(See especially 3.7 to 3.9 and 3.10 to 3.14)

By adopting an inclusive approach to sexual health, the strategy fails to state unequivocally what constitutes HIV prevention and who should be concerned with it as a specific endeavour.

Throughout the strategy, HIV prevention is confused with information-provision (as if this is its only component). In turn, information-provision is confused with the methods used to achieve it (most notably outreach). Greater uptake of HIV testing is also championed as a panacea for preventing HIV infections (4.48 to 4.55) on the basis of very little evidence and without ever articulating the process whereby it might serve to reduce the number of new infections.

PROPOSED ACTION:

- [3] Define HIV prevention and its purpose, scope and rationale. The definition in 3.10 should be replaced with a far more thorough and wide-ranging definition such as that outlined below:

HIV prevention aims to reduce the number of newly acquired HIV infections, by:
reducing the numbers of sexual, needle sharing and mother-to-infant HIV exposures, and by addressing directly those co-factors known to facilitate HIV transmission (such as the presence of gonorrhoea, the use of vaginal drying agents and high viral load).

This can be achieved by meeting people's HIV prevention needs, which are far more complex than information. They include: self-regard, regard for sexual partners, sexual choice, interpersonal and physical skills, access to condoms, lubricant and sterilised injecting equipment, access to information and technologies to reduce the likelihood of HIV transmission occurring during conception, awareness of the presence of infection and access to HIV and STI diagnosis and treatment.

These needs can be addressed by increasing access to, and the quality, of HIV prevention and other sexual health interventions.

3b. Financing and prioritising HIV prevention in wider sexual health provision

It is widely recognised that the long-established ring-fence around HIV prevention funds has not prevented their misuse. When these funds have been used to address HIV prevention needs, they have often failed to address those populations most likely to acquire HIV infection in the future: namely gay men and Africans. HIV prevention allocations have traditionally been underspent or misspent, with little accountability. Most importantly funds have been used to subsidise generic GUM services and specific anti-HIV drug costs and to support Health Promotion Units with limited commitment to HIV prevention. Health Authorities' use of AIDS (Control) Act Reports (1987) have been monitored and acted on with insufficient rigour to prevent these widespread abuses.

The strategy proposes eliminating the ring-fenced HIV prevention allocation and trusting that forthcoming changes in the NHS will improve HIV prevention services (see section 6.21). In addition it seems that HIV prevention is not to be designated a specialist service but 'mainstreamed' with other sexual health services administered by PCTs out of their main financial allocations. It is our considered view that this can only exacerbate historic inefficient and under-investment in HIV prevention, as well as existing inequalities in HIV infection, by:

- removing the very limited financial accountability that exists;
- substantially reducing the likely national spend on HIV prevention; and
- increasing already substantial competition for funds by placing HIV prevention spending in direct competition - at local and national levels - with other, less stigmatised, concerns such as unwanted pregnancy. HIV prevention will be lost within broader moral and financial imperatives of PCTs.

Responsibility for HIV prevention is soon to be placed with Local Multi-Agency Commissioning Groups (and confusingly also with Level 3 clinician teams, see our comments under 4a). As things stand there may be insufficient expertise in HIV prevention in these groups. Indeed, experience tells us that many will be prejudiced against the main groups affected by HIV: gay men and African communities.

PROPOSED ACTION:

- [4] We suggest that the abolition of the ring-fence around HIV Prevention funds be delayed for at least one year, while PCTs become familiar with their new roles and begin to understand what constitutes HIV prevention.
- [5] The Strategy should also incorporate the following points:
- Targeted HIV prevention activity is a necessary and vital part of every local sexual health strategy.
 - HIV prevention is highly cost effective even where it is only partially successful, given the huge costs associated with the treatment and care of people with HIV.
 - While HIV prevention activity is probably best provided by specialists with substantial health promotion experience (whether statutory or voluntary sector), it is also a function of all sexual health services including primary care and specialist out-patients services (such as HIV and GUM clinics).

3c. Targeting groups at substantial HIV prevention need

(See especially strategy sections 3.22/ 3/ 4)

The cessation of ring-fenced funding and the transfer of commissioning responsibility to PCTs has the potential to adversely affect the targeting and effectiveness of HIV prevention interventions.

The first difficulty concerns the potential for PCTs to prioritise the epidemiological and clinical aspects of HIV prevention at the expense of broader social and structural factors. There is currently a commitment on the part of health authority commissioners to work in partnership with voluntary sector agencies to develop services which, in addition to addressing clinical need, meet broader HIV prevention needs. Because PCTs currently lack the capacity to maintain this broader view of HIV health promotion, there will be an inevitable concentration on clinical aspects of transmission. Commissioning services from this perspectives can lead to major inefficiencies. For example, extensive attention is given to clinical intervention in vertical transmission while no attention is paid to the heterosexual HIV exposures that are occurring among African communities. Such exposures result both in HIV infections for men and conception for HIV infected women. Preventing these exposures is ***much more cost-effective*** than preventing transmission during childbirth.

The second difficulty concerns lack of expertise, ignorance and even prejudice among NHS commissioners which, when coupled with the other valid calls on NHS resources ensures that even ring-fenced funds are not allocated to work with gay men and Africans. Ensuring these same people are responsible for addressing that prejudice while simultaneously increasing the internal competition for resources simply will not work for HIV incidence.

As it stands, the strategy not only does not address these difficulties, but will make them far worse. It does this by conflating the causes of morbidity (infections and conceptions) in one section, then conflating the groups experiencing them in another, and finally putting these needs in competition with each other and all other health needs for finite funds. Because of the lack of expertise, ignorance and/ or prejudice amongst commissioners, 'young people' will come to mean 'heterosexual young women' who may become pregnant rather than 'young gay men' who may get HIV; 'black and minority ethnic groups' will mean those non-white groups that can easily be contacted rather than African people who may get HIV.

Thus already mis-allocated HIV funds will be further diverted away from those who will become infected. **We cannot state strongly enough that it is feasible that the strategy will foster HIV incidence, not reduce it.**

PROPOSED ACTIONS:

- [6] Separate the targets of the strategy (rates of unwanted pregnancy, HIV incidence, chlamydia incidence, HPV incidence, NSU incidence, HPV incidence, gonorrhoea incidence and syphilis incidence) from the priority groups that are affected by them. This would involve stating, directly and unequivocally, specific priority target groups for each of the main targets.
- [7] The Strategy should state unequivocally that local HIV prevention activity should be guided by **national** patterns of HIV incidence and what is known of the existence of priority groups in local communities. Thus, as a general rule, interventions and programmes of interventions targeting gay men and African communities should take precedence over interventions targeting groups who are easier to access but less at risk of HIV such as 'the general public'.
- [8] We reiterate the need to maintain the ring-fence on HIV prevention allocations for at least one year, until PCTs are familiar with HIV prevention activities.

4. Better services - levels of interventions

Chapter 4 makes the crucial distinction between an intervention (some specific activity carried out in a specific place, intended to bring a specific benefit to a specific person or group of people) and the potential provider of that service (primary care team, specialist sexual health provider, pan-PCT clinical teams).

We value the clarity this chapter brings to the planning and delivery of sexual health services, but remain concerned with three areas as it currently stands. These are outlined below.

4a. The value of non-clinical interventions

In level 3 (box on p.25) the phrases "outreach for STI prevention" and "outreach contraceptive services" need clarifying. Normally, "outreach" refers to activities whose prime aim is to bring people into a service centre. Activities whose aim is to meet sexual health need *in situ* are usually referred to as "detached work". We are unclear if these two interventions are clinical service provision in non-clinic settings (ie. detached work such as satellite GUM clinics) or the whole body of education and personal development activities that occur outside of clinic settings under the loose heading of 'outreach'.

This lack of clarity points to a major omission throughout the strategy, namely targeted HIV prevention activities. Prevention is about the future, something that has not happened yet. In meeting people's needs to navigate potential sexual health hazards, community-based services have much more to offer than clinical services. It is worrying then that the whole raft of HIV prevention activities currently commissioned by health authorities are not acknowledged in the three levels of interventions described.

We are also disturbed by the apparent assumption that 'prevention'='information giving' and that any provider of a clinical service is qualified to deliver any non-clinical prevention service (eg. counselling, personal development groups, educational small media, poster production, free condom distribution, peer education projects, community development etc.). Many of these interventions require specific experience and skills as we have already argued.

PROPOSED ACTION:

- [9] That the specialism of non-clinical HIV/ STI prevention be recognised, valued, and included in the levels of interventions, rather than described separately in Chapter 3.

4b. Sexual health needs assessment for local populations

The extent to which a service has an impact on increasing sexual health is in direct relationship to the extent to which that service is needed by the people who encounter it. This means that local population sexual health needs assessment will be crucial in determining the impact of local sexual health programmes. The paucity of guidance on the meaning and practice of population needs assessment suggests this is an underdeveloped area of the strategy and a major potential source of failure.

When the strategy defines sexual health needs assessment, it does not draw a distinction between identifying a population-level or individual HIV prevention need and assessing the extent to which this need is met in a local population. It is the role of the strategy to state what HIV prevention needs are. It is the role of local commissioning groups to establish the extent to which needs are met in local populations. The strategy already lists almost all the things people might need to increase and maintain their sexual health. It would be very useful to draw these together, and for this list to be the state of affairs against which sexual health need is measured. Similarly, throughout the strategy obstacles to people having these needs met are identified and these would form the basis of assessment of need for interventions to reduce or overcome these barriers. These could also usefully be drawn together.

In the current framework "sexual health needs assessment" appears to reside both with Local Multi-Agency Commissioning Groups **and** with Level 3 clinician teams. Given the social nature of the majority of prevention activity, we feel it unlikely clinician teams will have the required expertise to carry out such population needs assessment. It should reside solely with Local Multi-Agency Commissioning Groups.

PROPOSED ACTION:

- [10] Clarify that responsibility for sexual health needs assessment for local populations resides with Local Multi-Agency Commissioning Groups rather than clinical specialists.
- [11] Include a list of sexual health needs which the Department find acceptable for NHS funded interventions to address. These needs should include:
- autonomy and bodily integrity;
 - knowledge and understanding of sexual health and hazards;
 - positive self-image and interpersonal skills;
 - sexual confidence;
 - ability to use barrier protection;
 - access to barrier protection and contraception;
 - access to emergency contraception;
 - access to HIV post exposure prophylaxis;
 - awareness of probability and extent of potential harm in sex;
 - access to services to determine ones own HIV status (HIV testing);
 - access to services which can determine whether one has other STIs;
 - access to anti-HIV therapy;
 - access to treatment for STIs;
 - knowledge of available interventions.

[12] Include a list of common obstacles to people getting their sexual health needs met, assessment of the extent of which should occur locally in needs assessment. Interventions to reduce or overcome these barriers should be encouraged as valid HIV / STI prevention activities. These obstacles would include:

- embarrassment
- social exclusion
- exclusion from family life
- poverty
- homelessness
- no privacy
- alcohol or drug addiction
- HIV stigma and discrimination
- sexual stigma and discrimination
- racism
- homophobia
- Section 28
- asylum dispersal policy
- low educational attainment

4.c Qualities of interventions

In a wide variety of places within this chapter (and the strategy more broadly) minimum standards for interventions are alluded to. While this is more commonly done in relation to clinical interventions though guidance on clinical governance, for example, there are several attempts to generate more generic standards (4.79 to 4.82 for example). The impression is that the Department would like generic standards for all sexual health interventions.

PROPOSED ACTION:

[13] We suggest that this chapter set generic standards for all interventions intended to improve the sexual health of people living in England. This might take the broad form outlined below:

All sexual health interventions should:

- be feasible within available resources;
- prioritise the needs of those most at risk;
- be needs led (ie. should focus on those people's needs);
- be delivered as a part of a programme (a synergistic group of interventions) whenever possible;
- be acceptable to their target group;
- contribute to challenging stigma and discrimination;
- be equally accessible to all people they are intended to benefit;
- respect confidentiality and the right to privacy.

Local commissioning plans should aim to increase:

- the match between unmet sexual health need in the population and the interventions available to address them;
- the number of interventions available;
- the coverage (uptake) of all interventions by their target populations.

Need should be assessed against the above aims and obstacles, and interventions commissioned to address the needs most commonly unmet in the priority target groups.

5. Better commissioning

In terms of the overall structure of the Strategy, we feel that Chapter 5 (commissioning and provision structure) should come before chapters 3 and 4 (interventions to be delivered) as it sets the context in which these interventions are planned. It is certainly very much easier to understand Chapters 3 and 4, after Chapter 5 has been understood. Apart from this broad concern there are only two specific aspects of this chapter that we wish to comment on.

5a. What is local?

The establishment of Local Multi-Agency Planning Groups with identified lead commissioners will bring greater co-ordination and other seamless service benefits to local provision. However, in the case of population-level needs the definition of *local* seems problematic, especially in relation to health promotion and HIV prevention services. For example, very many years of specialist commissioning practice has led most of the Health Authorities in London to conclude that a high proportion of HIV prevention interventions for gay men should be purchased and delivered on a pan-London basis (such as free condom distribution, mass media development and display etc.) In the context of 30 PCTs across Greater London it is hard to see what 'local' will mean and how this will impact on current good practice.

PROPOSED ACTION:

[14] Clarify the meaning/s of 'local' and highlight circumstances in which attention to services across larger geographic boundaries than PCTs may be efficient.

5b. Core skills for commissioning

The commitment to local targets linked to national priorities, based on local needs assessment, user and professional involvement and partnership working is extremely commendable. However, for us, it raises a substantial set of concerns regarding research and evaluation expertise. In our opinion, the range and type of R&D expertise required by the strategy far exceeds that available in the current workforce - particularly in relation to NHS commissioners. It might be argued that this expertise is only needed within local commissioning groups, but this too brings to the fore substantial concerns about the training and skills of the workforce. As it stands, local implementation of this strategy requires a range of high level research and development skills. Taking examples just from Chapter 5:

- 5.3 "... every commissioning organisation must be able to show ... [an] understanding [of] local needs and identifying priority population groups."
- 5.6 "Assessments of the local need for services should: identify sexual health needs; highlight gaps in service or high levels of need; and take account of the wider, underlying determinants of health."
- 5.14 "Commissioners should reflect the aims of this strategy in their local plans. They should: ... identify action to meet the needs of targeted groups; ... define and monitor service standards for providers."
- 5.15 "HIV prevention plans should: .. set local targets; indicate the outcomes to be achieved; and describe the monitoring and evaluation process."

With the creation of PCTs, and devolution of responsibilities to them, more people will be in positions requiring research and planning skills than was the case with health authorities. The context within which these people make decisions are also expected to be broader.

PROPOSED ACTION:

[15] Instigate or support a local sexual health needs assessment and service planning training package for members of Local Multi-Agency Planning Groups. Commissioners must also be the targets of training as well as ensuring others receive it.

6. Supporting change

The Department is to be commended on its substantial commitment to supporting the widespread changes that the Strategy recommends. It is our view that the strategy as a whole needs a robust and long-term plan, to support and ensure its effective implementation. Our specific responses, below should be viewed within this larger goal.

The review of both the current data collection systems and the funding and co-ordination of research is especially welcome. We remain concerned with four issues in the chapter as it currently stands.

6a. Research priorities

In our view it is not helpful, in this enormously complex strategy, which will be implemented over very many years, to state specific research priorities or areas. These will inevitably change as the epidemic develops, as research is undertaken and published and as interventions become more focussed in areas of good practice. The listing of potential research priorities also seems at odds with the very welcome statement that the research agenda should be "identified by consultation" (section 6.8).

Recognising that research priorities will change constantly, the Strategy should set-up a forum (or multiple fora) where researchers, key policy and intervention practitioners, Departmental officials and key research funders can meet on an on-going basis to develop and refine research priorities.

If it is concluded that the final Strategy must include *actual* research priorities then many of those stated are sound. However, their breadth and depth vary enormously (some imply a specific hypotheses: the relationship between unsafe sex, drugs and alcohol; others an entire field of study - social exclusion). More importantly, other equally valid research priorities are contained in the document but not reflected in the *research priorities* listed - for example, "improve information on behaviour and attitudes", in section 6.4; and "strengthen research on the needs of people with HIV", in section 6.5.

PROPOSED ACTION:

[16] Exclude specific research priorities from the strategy, and commit to instigating and supporting an on-going fora to set and review research priorities across the strategy.

6b. Funding research

It is clearly appropriate that the Department, through the Policy Research Programme continue to fund epidemiological, social and behavioural research relating to HIV and sexual health. However, the direct practical relevance of much of the work historically funded through the Medical Research Council's (MRC) AIDS epidemiological research fund must be challenged. While some internationally significant University-based research has received funds through this route, its direct contribution to STI / HIV prevention and improving sexual health is marginal. It is unclear whether the MRC is the appropriate body to fund research into HIV prevention or sexual health promotion, since it lacks the appropriate expertise.

Any agency with responsibility for administering funding for research to support this Strategy must be encouraged to be guided by the research priorities that emerge in (or from) it. For this to occur, it is likely that far greater prominence must be given to applied social and behavioural research which is designed to inform best-practice. In view of the Strategy's recognition of the very variable state of the evidence base more priority may need to be given to realistic evaluation methods which are based on real and productive collaborations with service providers. These should seek to demonstrate equity, effectiveness and efficiency.

PROPOSED ACTION:

[17] Consider how best Departmental research monies might be administered for the maximal benefit of this strategy.

6c. Disseminating research and best practice

We welcome the commitment to develop “new ways of getting information to the people who are planning and evaluating local services” (section 6.4). We trust this will include the development and deployment of rigorous dissemination strategies for new research findings. The most brilliant research will only aid the implementation of the strategy if the researchers, funders and the Department make a renewed commitment to ensure their research and evaluation make a tangible contribution to best practice in the field.

PROPOSED ACTION:

[18] Consider how the Department might ensure that research might more directly inform best practice in the field.

6d. Professional education and training

The emphasis on education and training for those who provide services is to be commended, as is the statement that “everyone working within the field will need training to support implementation of this strategy”.

While NHS posts such as nurses and health advisors need specific development, the concentration on NHS posts in this section is of some concern. We assume the Department will require commissioning bodies to specify the target of professional development and training programmes to include people working in local voluntary and community sector agencies as well as local NHS providers. Such organisational interventions (professional training) should demonstrate how they are equally accessible to all their target groups. Above we pointed to the need for training to also explicitly include commissioners.

7. Miscellaneous - referencing

Reference 11, page 8 - excludes the authors and publishers location.

Hickson F., et al. Vital statistics: findings from the National Gay Men’s Sex Survey 1999. London, Sigma Research, July 2000. ISBN 0872956521.

Reference 20, page 14 - excludes the authors and publishers location.

Hickson F., et al. Vital statistics: findings from the National Gay Men’s Sex Survey 1999. London, Sigma Research, July 2000. ISBN 0872956521.

Reference 27, page 17 - error in the sub-title - excludes the publishers location and ISBN.

Hickson F., et al. Making it count: A collaborative planning framework to reduce the incidence of HIV infection during sex **between** men. London, Sigma Research, Second edition, September 2000. **ISBN 0872956505.**

Reference 34, page 33 - splits the title across the authors - mis-spells one author’s name - uses different date convention - excludes the publishers location and ISBN.

Anderson W & Weatherburn P. Taking Heart? The impact of combination therapies on the lives of people with HIV. London, Sigma Research, March 1999. **ISBN 0872956424.**

Section 6.6, page 44 - Sigma (**NOT SIGMA**) Research.